

## **What can practice learn from people living with dementia?**

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# What can practice learn from people with dementia?

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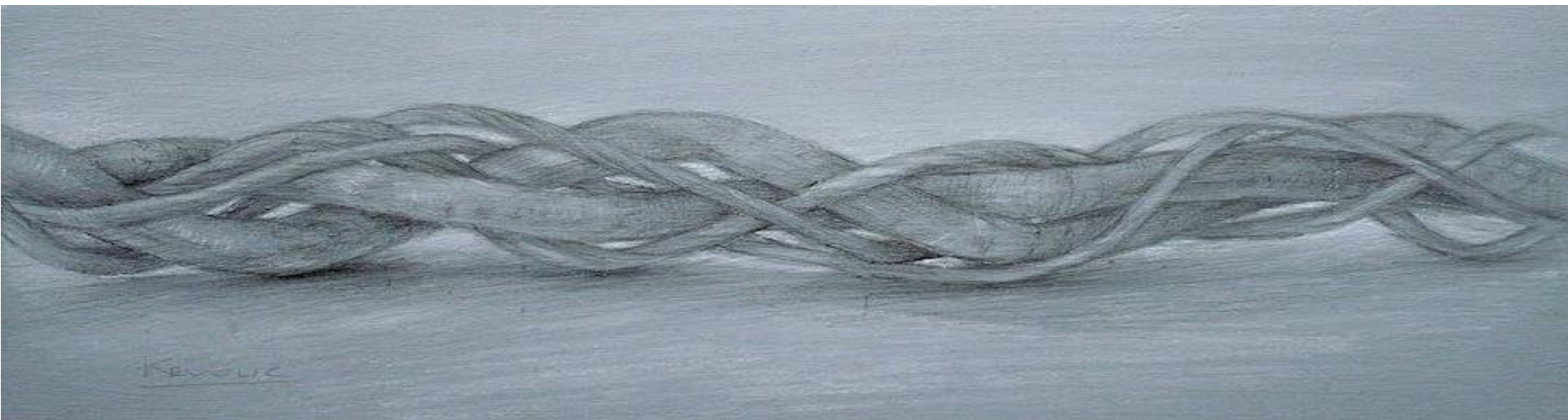
# I hope to invite you on 3 intertwined journeys today



Journey through history of ideas in the context of people with dementia:

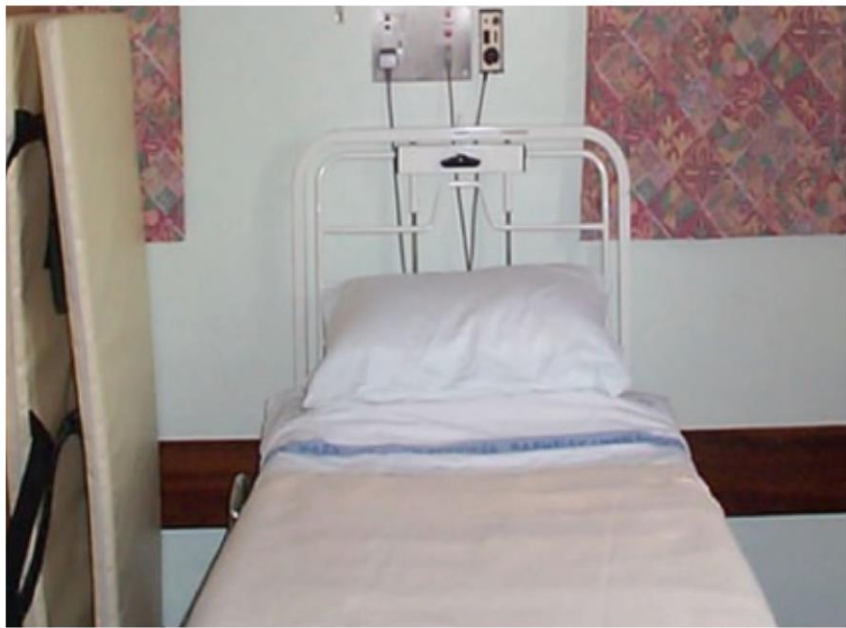
Journey which shares how these have shaped and been shaped by the experiences of people living with dementia

My own journey: how my life and my practice as a therapist, visual artist and design researcher has been shaped by the individuals I have worked alongside



# Starting points...





*people with dementia  
are sometimes seen as  
'unsuitable for  
rehabilitation'...arises  
because dementia is  
seen only as a process  
of degeneration*

Wey 2002



# Coming home...

## Warmth and humour:

'I never saw a cake like  
that' she said

'It's a papier mache  
bowl' I replied

'I don't like the taste of  
that my dear'





## Heightened emotional intelligence



*'The title is sunlight serenade'*

*It is called 'only eyes for you'. He thinks she is hopelessly in love with him (laughs) but what he doesn't realize is that she is looking at the dog!!*

*'A secret encounter': I don't think they are married by the way they are sitting. She has put the dog in the middle as a sort of chaperone.*

# Beauty of language

How beautiful it is. You can see all sorts of  
pictures in it. A man's face, all cross and  
angry

A jelly fish with its legs tangled up

The side of a map

Look where the water goes in

That part's like a trumpet

All bright and shiny

Ah look the red room

Champagne and rubies

But this one is my favourite

It's electroplasm





# Photography: glimpse into the person's world

We turn to the next picture which is of her bed bay. She pauses for a moment, thinking and then pointing to the blue carpet she simply states, 'this is the moat with the house where I live'. I am suddenly reminded of her reluctance to move from her own room and ask whether she likes it there. 'Oh no' she says 'I never learned how to swim.'



# Practice shaped by broader context

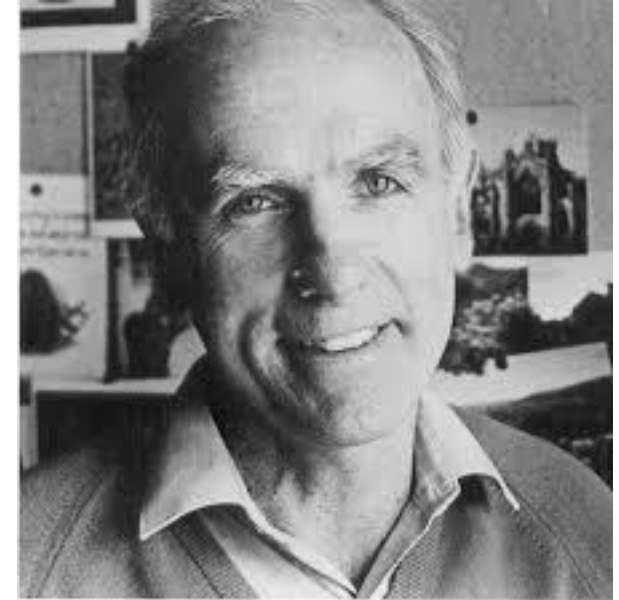


Alois Alzheimer



Auguste Deter

Bio-medical model



person with DEMENTIA  
PERSON with dementia

**But a status quo...and was viewed  
with suspicion...conversations  
under the car**

# Growing movement by people with dementia



# Setting the scene...

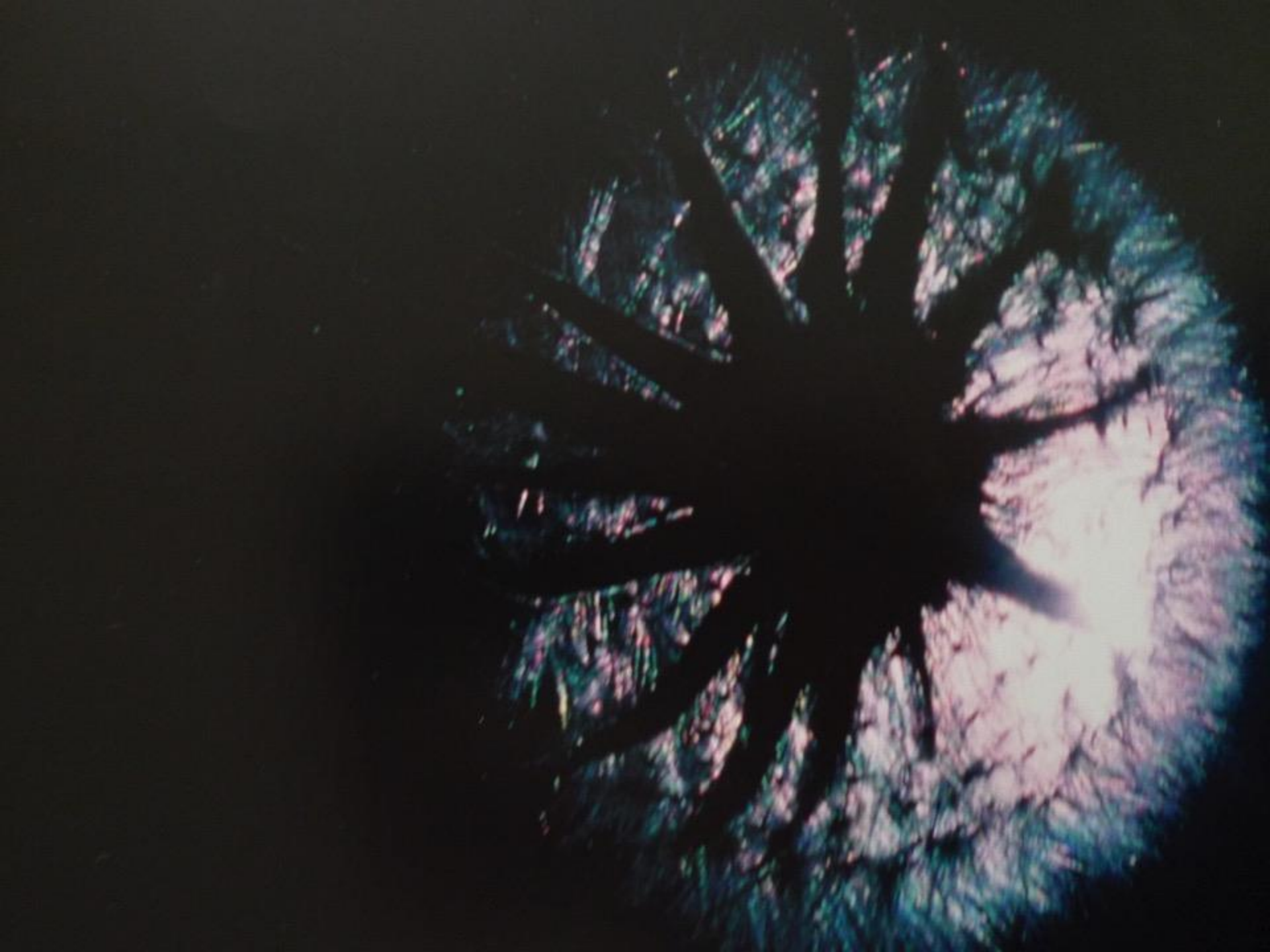
*I was still reeling from the shock of just having being diagnosed with Alzheimer's Disease. I picked up the phone and tentatively managed to ring the number for the Alzheimer's Association...the response was that there was very little available that would be suitable as most was directed towards the carer.....*

*Christine Bryden*

*Being told I had dementia led to a door reopening after a difficult time in my life. New challenges, new friendships. I wanted to raise awareness about dementia and show that people with dementia can re-learn forgotten skills as well as learn something new*

(James McKillop 2002)









William Utermohlen





I'm not dementia impaired. I'm  
communication impaired.



**Bob:** You touch the very little strings  
as I think in the centre of my heart.  
What do you think of that now?

**Maria:** *I touch the strings in the centre  
of your heart? Is that how you  
feel when you listen to the music?*

**Bob:** *Oh yes, Oh yes I do, yes. There's  
something in you, like, I suppose  
mental as well naturally and I don't  
know, you can't explain it, that's the  
way it is.*

# The arts as points of connection and communication













I want to thank you for listening  
You see, you are words  
Words can make or break you.  
Sometimes people don't listen  
They give you your words back  
And they're all broken, patched up



*AA poem is something that feels into my psyche. It is where  
it comes out and where it ends up --- essence of essences.  
What matters to me is the me-ness of it.*

## Defence

*Bobby was bigger than me.  
And when I got it, I got  
a right good thwack from this bloke.  
He just ladled into me,  
and I couldn't stotter, I was  
lying in the playground. Biff! Out.  
Bobby was going to get a doing.  
And I administered it.  
If you steam into me: Stars.  
I cloaked myself in my self*

*and that was good for me.  
I got that from him too.  
I had my dose,  
and Bobby had his dose.  
Big Al's bigger than me too,  
but I'm not going  
to lie down under his blows.  
He's in there. I can still  
cloak myself in my self.*

Listen for their poetry – when your participants lose their fear of self-expression they may find an artistic freedom that brings beauty out of disorder and confusion.

Selly Jenny

An artist, on seeing an exhibition of paintings by people with dementia said:

*I was told that a number of these artists were unable to communicate.*

*They often are reclusive and confused. Their paintings however are clear, straightforward, richly coloured and above all communicative.*

(Jenny and Oropeza 1993)





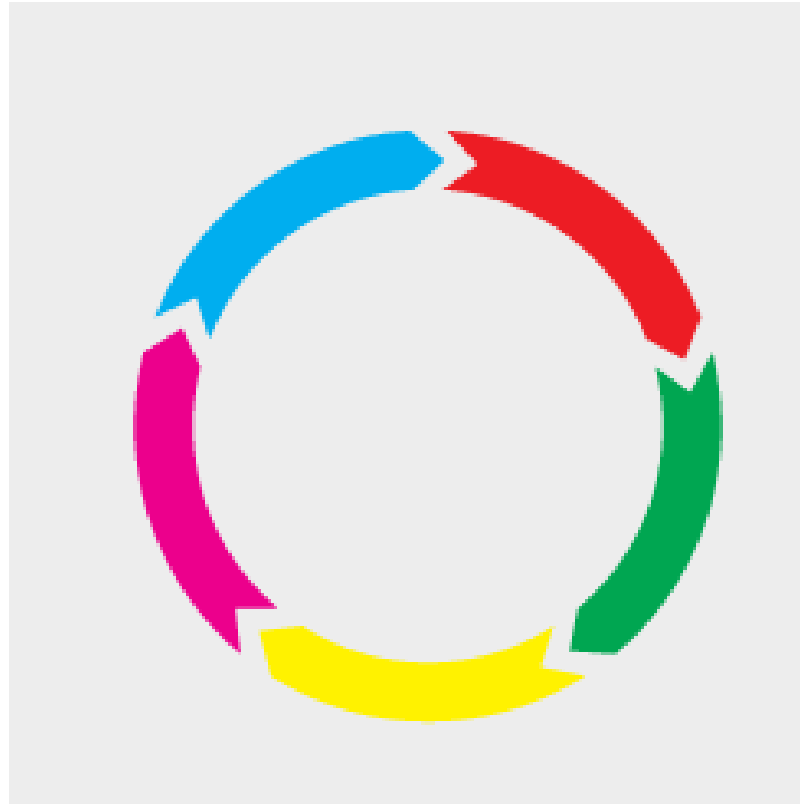


*my husband – he's an  
artist....*



Whereas a person with a physical disability needs modifications to gain physical access to their environment I need modifications to help me understand my environment.





About reciprocity: hearing, listening and responding and in doing so to affect real change for a greater number of people



Range of new methods  
recognizing importance of  
imagination and creativity –  
value for everyone e.g.  
Timeslips (Anne Basting)







# Artz for Alzheimers: Museum of Modern art (MoMA), New York



- MoMa: Meet me at MoMa – an educational programme specifically for people with Alzheimer's disease and their caregivers
- Meet me at MoMa gives those living with Alzheimer's disease an expressive outlet and a forum for dialogue through guided tours and discussion in the museum's galleries during non-public hours



- It's like he's trying to tell a story using words that don't exist," Mr. Rosen said finally of Picasso, fixing the painter's work with a critic's stare. "He knows what he means, but we don't.



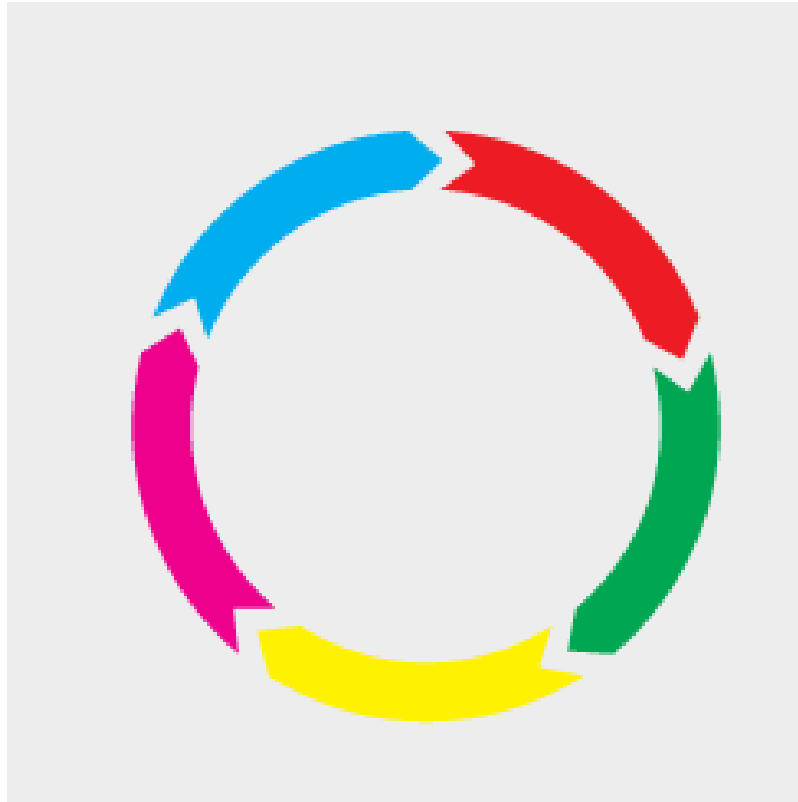
Later, in front of Matisse's "Dance," he was asked to provide a title for the painting, and on a notecard wrote "Dance of the Beauties." He smiled rakishly when asked to explain. "I see a naked woman?" he said, shrugging. "I think it's beautiful."

# Innovative approaches to research



- Blossoming of alternative approaches to research which lend themselves perfectly to people with dementia





Reciprocity: broader context – dementia as a disability, calls for  
community for more dementia-supportive environments  
People with dementia showing design, creative practice new  
possibilities



An abstract sculpture made of white, thick, rectangular beams arranged in a complex, overlapping geometric pattern. The structure features numerous triangular and polygonal openings, some of which are illuminated from within, casting a warm, yellowish light. The beams are set against a dark, neutral background, creating a strong contrast and highlighting the three-dimensional form and the play of light and shadow.

**Not enough:  
Designing for  
thriving**

*We need to focus on enhancing our remaining abilities and compensating for any losses and maybe even working towards a new perspective of daring to try to recover skills, develop new talents and create a new future invested with meaning and hope.*

Christine Bryden, 2005

Journeying through Dementia is a community based intervention which aims to support people at an early stage of their dementia journey to engage in **meaningful activities** and maintain **community connectedness**.



# The content of the programme

How to do the things I enjoy.  
I don't want to sit around  
talking about dementia all  
the time. It's depressing!

Ways to maintain  
meaningful roles such as  
volunteering, it's the one  
time that people treat you  
like a person, it gives you  
distance you know.

# See the whole person and recognize the complexity of people's lives

We have other things to cope with – not just dementia, 'it's hard enough getting dressed, never mind putting one of these [pointing to splint on hand] on here'

Give the person with dementia some hope to cling onto. Show them that dementia makes you change your life but you can still be happy and productive.

'Once you've met one person with dementia, you've met one person with dementia'



# Facilitation of sessions: the atmosphere

- Sessions should be enjoyable. Living with dementia is difficult at times and the last thing you want is to go to a meeting that is dull and depressing.
- We don't just want to talk about dementia. We spend enough time thinking about it, we want to have some fun.



# The structure of sessions

- I found out the hard way that people with dementia do not have a great attention span. I run my meetings with an informal session: tea, coffee and biscuits half an hour before the starting time
- I do not plan to go on longer than an hour...people can stretch their legs and go outside for a smoke. If you go on too long you lose the smokers!



# Where groups are held: the environment

- Noise can be very distracting and it can be difficult to follow lots of conversations when they are all happening at once. It's helpful to talk in small groups and if everyone is speaking to the whole meeting, people should take it in turns so that others can listen.



# Involvement of carers?

- Yes....but...
- I think, and it is a personal thought, not an official one, is that carers and people with dementia should have their own distinct groups
- My initial thoughts are that some things might be done better together to save time having a specialist speaker having to come twice...both parties will be in their own state of shock and hopefully both being together at the one event will remember what has been said.

- People with dementia will want to get to know others and talk on their own terms. They will have to try and rebuild their self confidence and not be looking over their shoulder at their carer. They may talk confidentially among their peers and share worries but not repeat them with the carer present in a group in case they upset and distress their loved one.
- So you see the dilemma. Free speech, honest dialogue and thoughts can be constrained through no fault of anyone. Each wanting to protect the other. Do you without dementia speak differently when your partner is in the room? Yes!! Well we are no different.



## Journeying Through Dementia

Created By Lab4Living



Understanding Dementia



Relationships



Keeping Physically Well



Keeping Mentally Well



Dementia and Daily Living



Building and Developing Skills



Keeping Connected



Planning for the Future

### Meeting new people



Resource 1.3



### Asking questions



Resource 1.3



### Discussions



Resource 1.3



### Sharing worries



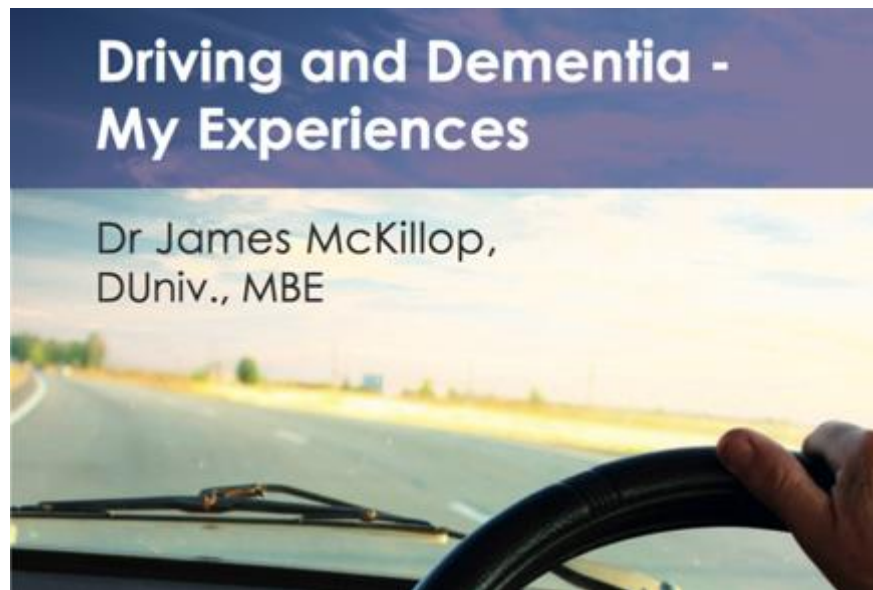
Resource 1.3



"I felt disempowered because the people that spoke to me about dementia always spoke about my loss – all the negative things. Nobody ever said "there are things that you've lost but there are also things you could gain." They never really took me from the loss of power into the action"

## Driving and Dementia - My Experiences

Dr James McKillop,  
DUniv., MBE







## All about the pack

The pack is full of handy **information, tips and resources** to help you, enable you to retain your independence and engage in hobbies and activities that you enjoy.

The pack is divided into the following categories each containing the following:

- **Information**
- **Tips**
- **Resources**





Learning something new

*What you've done for us has got me to the top...its put me back where I used to be..what we've been doing in here and saying and thinking has done me so good. I feel like a new person...I'm not showing off...you got me there honestly...if you'd seen me not too far back...off my food...coming here is the thing that got me back to the top.*

*I've got confidence. Yes, it's confidence what held me back...that's what you've given me*

*Rather than just talking I've been able to learn things about what I can do to help myself*



*You need a medal and a raise. I'd love to buy you a gold  
ring....if I were a moneyed woman I'd see you all right*

*You know you're telling me things that could alter my life*

*Having a laugh about some things alongside learning.*

*It's not long enough but there must be that many waiting for you  
It wants to continue because there's lots after us*

# The Life Café: end of life care



# The next chapter....

**Need to continue listening and finding ways to listen: we still have much to learn from people with dementia**

## The principles

These are the Scottish Dementia Working Group research sub-group core principles for involving people with dementia in research.

### Core principle 1

## I never heard what happened

### Principles:

- ▶ We want to be valued, and to be kept involved and informed.
- ▶ Good research gives you something after the end.
- ▶ There is a risk that people with dementia taking part in research can be “used” by researchers.
- ▶ Research should start from a place of seeking positive and lasting change in our lives, and in the lives of people with dementia in the future.
- ▶ It usually takes several years and more than one research project for positive and lasting change to happen.



**This means that:**

- Researchers should ask people with dementia how they want to be involved in research, including at what points and in what ways they want to be updated. Different people will have different views on this.
- We want researchers to come back and tell us the outcome of research that we have been involved in. Please be honest and don't bury "bad" findings.
- For many of us, keeping us involved means keeping our families (or a trusted person who we nominate) involved and informed too.
- In order for research to make a full impact, professionals and others in our communities need to be involved and informed about the outcomes of research in ways which reflect their involvement in our lives.

# Re-consideration of ethics in co-production



- *In December 2014, I came across one of my own poems on Twitter titled ‘Lost’ (2010, 2012) that appeared to be attributed to other authors, although I wish to state clearly in no way was it unethical in the research process or the way it was cited and in no way did this pilot study then published by Petrescu, MacFarlane, & Ranzijn (2014) breach any ethical protocols. The way the poem was published on Twitter was what caused me to notice it in the first place, which was as “‘Lost” (Petrescu & McNab)’, rather than as the author [me] who owned the creative copyright.*

*The research community have to adhere to stringent ethics guidelines and constraints, so it seems clear to me that anyone else including organizations and charities who are actively engaging in co-production with people who have changed or reduced capacity including dementia, should be morally and ethically obligated to do so as well.*

# Reconsideration of how we acknowledge the contribution individuals make



*I have to ask why are the people who are providing this content not usually the ones funded to present or at least co-present it? A 2 or 3 minute video clip of people looking happy and contributing is not the same as presenting the work for themselves and it suggests tokenism and exploitation. It also makes them appear as research subjects or participants not as co-contributors.*

*Kate Swaffer*

# Where and how research is shared



*There are also huge career advancements for individuals presenting work at conferences and events, and I have often likened conferences to career launching pads. I have attended many, and so far have found very few things I listen to that actually make a real difference to the daily lived experience of real people living with a dementia and so often, it looks more like a social club with the same people in attendance.*





**Challenging the  
dominant discourse....**

# Employment

*Charities and private businesses dedicated to dementia can play a vital role: as well as fundraising and applying for grants, they can and perhaps should also take the lead on this, as they have predominantly been the organisations who have promoted consumer engagement and co-production. Employing people with dementia in their work would be an excellent place to start.*

# Reflections on the journey travelled.....



- Travelled quite some distance:
  - Dementia as a biomedical condition
  - A more relational understanding – seeing the person beyond the medical condition
  - Now moving towards the importance of embedding responses and relationships within broader socio-political practices and discourses: citizenship model

# Time is right: citizenship offers important frame



- Opportunities for growth to have one's self recognized in a holistic way beyond simply that of a person with dementia; to retain purpose in one's life irrespective of diagnosis; to participate as an active agent in one's life; to create a sense of solidarity and belonging with others; and importantly, the right to live life free of discrimination.
- Moving from independence to **interdependence**

# Dementialab

The real voyage of discovery consists not of  
seeing new landscapes but in having new  
eyes...Proust



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